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Communication of information about oral and oropharyngeal cancer: the quality of online resources

Running title: Quality of online resources for oral cancer

Key words: oral cancer, oropharyngeal, online resources, patient information, quality assurance

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Abstract

Aim: To critically appraise the content, quality, and readability of websites that provide online information about oral and oropharyngeal cancer and are accessible by people diagnosed with that condition.

Material and methods: Three popular search engines were used to find websites providing information about oral and oropharyngeal cancer and all links that presented on the first page of the search were analysed. Included sites were assessed for content (intended audience, and evidence of quality assurance). The validated DISCERN tool was used to assess the quality of sites. A readability score was calculated. Descriptive and inferential statistical analyses were performed.

Results: One-hundred-and-sixty-two web sites were examined. The majority (87%) were written for a clinical audience. Most (89%) did not display evidence of quality assurance. The median overall quality (DISCERN) score was 2.0, indicating potentially serious shortcomings. There was a correlation between the DISCERN scores and evidence of quality assurance certification, but this was not seen for readability.

Conclusion: The quality of on line information that may be accessed by people with oral and oropharyngeal cancer when seeking information online remains poor.

Clinical Relevance

Scientific rationale for the study: Web-based healthcare information is an increasingly important supplement to consultations. Many people diagnosed with head and neck cancer seek information about their condition and treatment from the internet.

Principle findings: The quality and readability of readily available and frequently accessed websites about oral cancer are poor.

Practical implications: Care should be taken when referring patients to the internet for health information. Both patients and clinicians must contribute to the development of online resources to ensure that the information communicated is accurate, useful, and understandable for all readers.

Introduction

Around 7000 people are diagnosed with head and neck cancer in the UK every year. The overall incidence is rising with increases of between 30% and 66% seen over a 15 year period (1). The diagnosis and treatment for oral and oropharyngeal cancer can be psychologically distressing because of the potential for profound changes in speech, swallowing, sight, hearing and appearance (2, 3). Before embarking on treatment, therefore, it is important that patients are well informed about what may happen to them. However, the potential impact of the condition and its treatment on physical and mental wellbeing and ongoing quality of life (4-6) as well as the distress of the diagnosis and treatment may mean that people remember less than half of the information that they are given during consultations (7, 8).

A written format is the most popular way of providing supplementary healthcare information and leaflets are regularly given out by health professionals providing care for those with head and neck cancer. Increasingly patients and their carers are also turning to the Internet for healthcare information (3, 9-13) but the quality of online information has been questioned. Although one study has concluded that websites containing information about potentially malignant conditions were of acceptable quality (14), others (15, 16) report that the quality of on-line information about head and neck cancer was poor, particularly with respect to information about quality of life. Online health resources are often reported to require a high reading age and are therefore potentially inappropriate for people with head and neck cancer (16). Anecdotally, they are often aimed primarily at a clinician readership rather than delivering information that is more relevant to a patient perspective. It is also important to note that internet resources for head and neck cancer are rarely subjected to quality assurance (15, 17, 18) and so there is no certainty that they are accurate or

contemporary. This is important because the information accessed should be concordant with what is discussed during consultations to avoid patients becoming confused or anxious about contradictory accounts.

In 2009, the quality of websites providing information about oral cancer was assessed as being poor (15). We considered it timely to update this analysis because the availability of online information continues to increase and patients are increasingly likely to refer to web pages for health care information (13). We assessed websites returned from a broad range of search terms by three popular search engines and attempted to mimic the search strategy that lay people typically use when searching for information on the web (19, 20). Our aims were to 1) evaluate the quality and readability of websites about oral and oropharyngeal cancer patients that were returned after an unsophisticated search for online health information and 2) to assess whether the information available on these websites was aimed primarily at clinicians or patients.

Materials and methods

Search strategy and eligibility

Between December 2012 and January 2013 we used Google (www.google.com), Bing (www.bing.com), and Yahoo (www.yahoo.com) search engines to find websites containing information about oral and oropharyngeal cancer. These engines were the most frequently used search sites at that time (21). We used the following comprehensive, but not exhaustive, list of search terms: *oral cancer, mouth cancer, head and neck cancer, oral tumour, mouth tumour, head and neck tumour, tongue tumour, tongue cancer* and *throat cancer* to find relevant web pages. Each link that was listed on the first page was clicked on to open the website. The first page that appeared was

analysed along with subsequent pages that were not more than one level down (one click away), in an attempt to replicate the search strategies of members of the public (20). Previous search histories were deleted before undertaking this research in order to try and restrict “adaptation” by the search engine. The first ten results per search term from each search engine were included in the analysis. Sponsored links were excluded and duplicate links were eliminated.

Content analysis

Websites were analysed with regard to i) whether they informed the reader from a clinician or a patient perspective (the clinical perspective was represented by the use of clinical and technical terms and a focus on clinical issues whereas a patient perspective was targeted toward people (and their families) with symptoms or a diagnosis of HNC) and ii) whether quality assurance was indicated i.e. whether or not the webpage displayed awards representing quality assurance (Health on the Net (HON) code (22) and The Information Standard (23)). The HON code certificate (22) is an ethical standard awarded to websites in order to demonstrate an intention to publish transparent, useful, objective and accurate information. It is based upon eight principles: authoritativeness (identifies the author and his/her training and qualifications), complementarity (intends to support, rather than replace, the patient-doctor relationship), privacy (a description of privacy and data protection policies), attribution (date of creation and last modification date, sources of medical content), justifiability (evidence to support health claims), transparency (purpose of the website: mission, purpose and intended audience), financial disclosure (declaration of funding sources and conflicts of interest) and advertising policy (a statement to explain the distinction between editorial and advertising content. Similarly, after rigorous

assessment by accredited certification bodies websites may be awarded The Information Standard certificate for being clear, relevant, evidence-based, authoritative, complete, secure, accurate, well-designed, readable, accessible and up-to-date (23). The HON code is used internationally (22) and The Information Standard is intended for websites aimed at UK patients (23).

An individual assessment of quality was made by FB using the DISCERN instrument (24), a reliable discriminator of both low and high quality publications (25). This can be used by both health professionals and the general public to assess the quality of written health information (paper based and online), regarding treatment choices (see Table 1). The quality of information is assessed with responses to 15 key questions answered on a 5-point scale (1 = “no, the quality criterion has not been fulfilled at all”; 2-4 = “partial fulfilment of the criterion” and 5 = “yes, the quality criterion has been completely fulfilled”). The first eight items test reliability of the publication, assessing whether it can be considered a trustworthy source of information regarding treatment choice and the remainder assess specific details about the information regarding treatment options and quality of life. There is also an overall quality rating which is “based on the answers to the [previous] questions”(24). This is scored as 1= serious or extensive shortcomings, 3= potentially important but not serious shortcomings and 5= minimal shortcomings.

Assessment of readability

A readability score was calculated using the SMOG (Simple Measure of Gobbledygook) tool (26). This tool was selected because it is the readability score adopted by the National Cancer Institute (27).

SMOG scores (26) are calculated by selecting 30 sentences - 10 consecutive sentences from the beginning, middle and end of a document - and totalling the number of words with three or more syllables. Detailed calculation is reported elsewhere (26). SMOG scores of 9-10 indicate the literacy level required for adults to be able to understand price labels on pre-packaged food or pay household bills (28). An ability to read material with SMOG scores of 13 and above implies education to GCSE level (grades A*-C) in the UK or the equivalent of a college education in the USA (28).

Statistical Analyses

Descriptive and inferential analyses were carried out using SPSS for Windows (version 16.0: SPSS® Inc., Chicago, IL, USA). We calculated medians and inter-quartile ranges (IQR) for the categorical DISCERN score and means and standard deviations (SD) for the SMOG scores. The chi-square test was used to determine evidence of differences between groups according to quality assurance for the DISCERN score and t-tests were used for inferential analysis of the SMOG scores.

Results

Search results

The search strategy yielded a total of 270 websites in the Google, Bing and Yahoo search engines. After elimination of duplicate links 162 websites remained and were included in the analyses.

Content analysis

One hundred forty-one websites (87%) were written from a clinician's perspective and nine (5.6%) from a patient perspective. Both patient and clinician perspectives were

present in four websites (2.5%) and 12 websites (7.4%) lacked a clear and defined perspective of any sort. Thirty one websites (19%) stated an aim of some sort and of these, 21 (68%) were rated as having achieved their aims.

In order to determine how concurrent the websites were, we looked for an updating or review date: thirty eight (23%) websites had update or review dates but these ranged from 1985 to 2012.

Fifteen websites (9.3%) carried the HON code certificate and six websites (3.7%) carried the Information Standard certificate. Three websites carried both (2%). The majority of websites (n = 144, 89%) carried no certificate.

Quality assessment

The median score and IQR for each of the 15 DISCERN items are presented in Table 1. For the overall rating of quality for websites (question 16 of the DISCERN), the median (IQR) score was 2.0 (1,2). This means that websites are rated as having important and potentially serious shortcomings(24).

With regard to individual items, two DISCERN items partially met the criteria for good quality: these were item 3 'Is it relevant?' (median =2.0 (IQR 1,3)) and item 6 'Is [the website] balanced and unbiased?' (3.0 (3,3)). All other items had median scores of 1 or 2 meaning they did not meet the criteria for good quality written information.

Assessment of readability

The mean (SD) SMOG score was 13.1 (3.0) requiring an education to GCSE (A*-C) level in the UK or a college education in the United States (28).

Quality of information (DISCERN) and readability (SMOG) as a function of quality assurance

Websites had different DISCERN scores as a function of whether or not they had been awarded a certificate of quality assurance ($p < .001$). The overall median (IQR) DISCERN score for HONcode certified websites was 2.5 (2,3) and for those with Information Standard certification was 4.0 (2,4). Websites with no certification had an overall median (IQR) DISCERN score of 1.0 (1,2).

There was no evidence of a difference in readability according to whether or not websites had been awarded either a HONcode certificate (SMOG scores = 13.5 and 13.0 respectively, $p = 0.55$) or certified with an Information Standard or not (SMOG scores = 12.9 and 13.0 respectively, $p = 0.92$).

Discussion

The findings of our study suggest that the quality of online information accessible by people with oral and oropharyngeal cancer is poor. This supports similar findings previously reported by Lopez-Jornet (2009) (15). Although many websites from around the world can be accessed using search terms related to oral and oropharyngeal cancer, the majority are not quality assured, their aims are not clear, the quality of the information they provide is poor, many are potentially out of date and they have a

relatively high readability level suggesting that they may not be accessible for many people diagnosed with this type of cancer (16).

This is important because people with cancer want high quality information about all aspects of their disease and its treatment. The potential benefits of being well informed include improved coming to terms with the disease, preparing for treatment, reduction in anxiety and potentially better clinical outcomes (29, 30). Our results also suggest that the information available about quality of life for those diagnosed and treated for oral and oropharyngeal cancer is lacking despite this being one of the areas where patients and their carers require more support (8). Even websites awarded HONcode and Information Standard certificates require a relatively high literacy level and so may be inaccessible to many people who might benefit from them.

This study has several strengths. We undertook a comprehensive assessment of the quality of available websites for oral and oropharyngeal cancer using validated assessment measures. The findings from each of the independent quality assessment measures were consistent and support our argument that the quality of these websites is poor. Before undertaking each search, the previous search history was deleted so we can be reasonably sure that the websites that we examined were novel and not the result of an adapted search based on previous location and language data. The searches were contemporaneous and, as far as possible, mimicked the search strategies of lay peoples' searches for healthcare information (19, 20). Some of the strengths of the study might also be considered as potential weaknesses. Lay search strategies tend to be restricted and limited (19, 20) and it may be that we have missed information, rendering our findings inaccurate because our search strategy was not exhaustive. However, if our

searches did not find all sites, there is little reason to suppose that the searches of other lay users would be any more successful. We did not assess the amount of traffic to each site but understand that search results are based upon the frequency of access with the most popular sites being returned first. Given our aim to mimic the search strategy of lay users we believe it was appropriate to focus only on the first page of returned links rather than to undertake a more sophisticated search. The contemporaneous nature of our search means that our data and therefore our findings might be considered obsolete: the use and popularity of search engines changes over time and so it may be impossible to replicate our methods and therefore our findings. Perhaps more importantly, the analysis of these websites was undertaken by one healthcare professional with a clinical interest in head and neck cancer (FB) and this, together with the fact that one of the measures – DISCERN – is subjective means that there is potential for biased reporting. However, because FB has a specialist clinical interest, we might have expected less awareness and therefore less criticism of the clinical versus lay perspectives and, consequently, higher ratings of quality when using a subjective measure. Although DISCERN is subjective, it is accompanied by detailed guidance on how to use it and the conclusions reached are supported by the objective findings of the quality assurance and readability assessments that we carried out. It has also been reported to discriminate reliably between written material of both low and high quality (25). This allows us to be reasonably sure that, overall, the quality of websites about oral and oropharyngeal cancer is poor and that our conclusions are reliable.

The implications of our findings are that the online resources available for patients and carers with oral and oropharyngeal cancer are potentially inappropriate. Information is often communicated from a clinician's perspective e.g. using technical terms and

focussing on clinical outcomes and the reading age of available websites is suited to individuals who have a relatively high level of education. Government policy in the EU and USA has highlighted the need for accessible, patient centred resources that can be used either to aid clinical consultations or that patients and carers could be referred to for their own self-directed research (31-33) and such sites are coming online, e.g. cancerresearchuk.org, healthtalk.org, Macmillan.org.uk, the Merseyside Regional Head and Neck Cancer Centre website (34) in the UK and abroad, Krebs Informationsdienst (German) (35), Ligue Suisse Contre le Cancer (Swiss) (36) etc. Similarly, the World Health Organisation has highlighted opportunities to develop the field of mHealth in order to benefit public health. Currently, mHealth is defined as medical or public health practice supported by mobile and other wireless devices (37). Using the concept of Raising Awareness (37) it advocates the use of mobile and online technology so that individuals can access appropriate health information on demand. In order to ensure that online technology is accessible, useable and reliable web developers would be well advised to consider the development of their resource in the light of a variety of quality assessment tools as described here. In addition, tools such as the Minervation LIDA Tool (38) designed specifically for the use of web developers working on health information sites will only improve the quality of such resources.

It is important for health care professionals to support patients' use of the internet when seeking health information because they are in a position to be able to judge the accuracy, relevance and quality of individual sites and to direct patients appropriately. The addition (and publication of the importance) of quality assessment awards such as HON Code and Information Standards would help to increase confidence in sites that were considered to contain accessible, useable and reliable information. This has

potentially beneficial outcomes for all parties – consultations can be supplemented with accurate and relevant online information rather than the sometimes less accurate and inappropriate resources that patients and carers to bring to consultations (8). Similarly, patients will have access to good quality and accurate information that is pertinent to their own situations, that addresses queries highlighted by clinical tools such as the Patient Concerns Inventory (39) and that they can access little or as much as they want to in their own time.

Previous research (13, 40) has shown that those people diagnosed with head and neck cancer, along with their families and carers, would like tailored access to online information about the condition, its treatment and ongoing quality of life from others in similar circumstances. This study has shown that currently available resources are of poor quality, often inaccessible and mainly written from the perspective of the clinician.

Conclusion

Given the increasing tendency of individuals to seek health care information and resources from the internet, websites that are evidence-based, easy to read, quality assured and written from the perspective of the person with the disease are necessary in order to improve the communication of relevant information to patients, their families and carers and also service providers.

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